Wessex
Academic Health
Science Network

NHS

Health Inequalities and Written Medicine

Round table discussion report
November 2021 Version 1

@WessexAHSN
wessexahsn.org.uk

TheAHSNNetwork

Contents

Key themes

Covid has undoubtedly exposed many of the elements of health inequalities experienced by patients in England.

Language skills, in particular not speaking English at all or not having English as a first language, can be a key barrier to accessing healthcare and, importantly, to taking medicines well.

The impact of not understanding medicines instructions is clear, not only in purely health terms but also in economic terms due to opportunities lost, poorer health outcomes and a dissatisfactory experience of healthcare for patients.

During the pandemic, pharmacy teams have done much to try to support patients and their carers with language barriers.

The impact of poor language skills is significant but can be addressed.

Written Medicine is a tool which supports medication labelling in languages other than English. This round table discussion was held to explore how the tool could be more widely deployed within pharmacy teams to ensure patients understand their medicines, and to support compliance with the General Pharmaceutical Council standards around patient-centred care and effective communication.

Wessex
Academic Health
Science Network

Introduction

The Covid-19 pandemic has highlighted the health inequalities that exist in England.

This round table event brought together pharmacy professionals, from all sectors, to discuss the issues that Covid has exposed. The event focussed on how language barriers in relation to medicines could be resolved and, in part, help address the health inequalities that are established when a patient does not have English as their first language, or where reading medication instructions is problematic.

Attendees

Lama Bendak Representing patients with little or no English

Amandeep Doll Royal Pharmaceutical Society

Mary Evans Chief Pharmacist, Bedfordshire Hospitals NHS Foundation Trust

Clare Howard Clinical Lead for Medicines Optimisation working with Wessex AHSN (Chair)

Angela Kam The Pharmaceutical Journal

Ghalib Khan Written Medicine and NHS England Clinical Entrepreneur

Helen Kilminster Clinical Director, People's Health Partnership Primary Care Network (PCN)

Laura McClintock Associate Director, General Pharmaceutical Council

Artur Pysz Community Pharmacy South Central

Samantha Quaye Pharmacy Business Performance Manager and Inclusion Ambassador, Barts Health NHS Trust

Frank Ratcliff Director of Industry and Innovation, Wessex AHSN

Background: Long term conditions

According to the 2011 census and the Home Office, three million people speak English poorly or not at all and 1.5 million have a learning disability. Yet in the NHS, in England, there is no direct policy or regulation to mandate that medication labels are available in languages other than English.

A study by Aston University in 2013 reviewed over **7,000 GP records** in the heart of Birmingham and demonstrated a correlation between language barriers and poor adherence to prescribed medicines. This issue impacts on patient safety, quality of life, life expectancy and medication safety, and hinders or prevents patients from getting the most benefit from the medicines prescribed to them.

To find out more visit: **pubmed.ncbi.nlm.nih.gov/24293338**

Language barriers also have a financial impact on the health system. If a patient does not know how to use their medicines, they may not take them, they may overdose, they may revisit the GP and/or may experience an unplanned hospital admission.

As well as language, it is important that we also are mindful of other barriers such as cultural taboos. For example, in some cultures, women may find it very difficult to talk to male health care professionals about sensitive subjects. If interpreters are not available, patients have to rely on friends or children thereby forgoing their right of confidentiality. This increases the likelihood of a suboptimal consultation with the health care practitioner.

Written Medicine was created due to its founders experiencing communication barriers in the hospital and community pharmacies they worked in. Their innovative and evidence-based products enable healthcare professionals to provide personalised accessible medication information to service users with language and communication barriers, in a bilingual format and illustrations via:

- **Pharmacy dispensing label**
- **E-discharge**
- **Prescription**
- **A4 medication summary**

This person-centred care intervention improves healthcare professionals' engagement with service users, removing ambiguity and giving them a better understanding of their medications. The evidence shows improved:

- **Adherence**
- **Patient and Medication Safety**
- **Communication**
- **Patient Experience**

The University of Portsmouth studied **151 patients** in **12 community pharmacies** across London and found **58% (n=88)** of patients thought they were taking their medicines correctly. However, following provision of a bilingual medicine label to the patient, they reported an improved patient experience. **62% (n=46)** noticed they were taking their medicines in a way other than specified on the label. **83%** of patients believed the translated label allowed them to use the right amount of medicines as specified on the label. **79% (n=101)** wished to received labels on a regular basis in the future and **66% (n=84)** said that this would consequently influence their choice of pharmacy stating that they would always or mostly visit a pharmacy offering such a service.

To find oit more visit: **ncbi.nlm.nih.gov/pmc/articles/PMC6473342**

Health inequalities: What does this look like now to pharmacists?

CH: Covid has shone a spotlight on the issue of health inequalities. What has been your experience of health inequalities and how Covid has influenced this?

HK: 55% of West Birmingham residents are from an ethnic minority and I have seen there is a massive gap due to lack of understanding, poor access – as well as English as a second language. There is huge social deprivation and there has been a significant, multifactorial impact on mental health, wellbeing, and the risk of Covid. We see large families in cramped housing and education is lacking. We were struggling to convey how severe this infection would be in households of twenty. We tried to explain about social distancing.

Within pockets of the population, we saw they had reservations regarding the Covid vaccine. What we struggled with was capacity to have one-to-one conversations. Many people just needed someone to listen to their needs. If they could access a smartphone, video consulting was excellent but also disheartening. We felt helpless that we couldn’t go out to home visits, as we would be at risk. As general practice goes it was a tough time; and the volume of calls was up to **180% higher**.

I’ve spoken to Ghalib about endorsing Written Medicine for my Primary Care Network (PCN). We now have an expansive team and I’m keen to foster this as a tool we can use to empower patients to take control of their health. Diabetes is a major issue for us; we have seen complications during the last 18-20 months, and that has been horrific. The gap in health inequalities is large, language is one part but also disabilities, ageing population and learning disabilities. These are vulnerable people and there is not enough resource to help them.

CH: Isn’t it that these issues were always there but now they are much more visible and obvious to us and can no longer be ignored?

ME: Clearly it has been a difficult year. We have had fewer outpatients coming through the hospital as we went ‘virtual’. In terms of issues, our healthcare workers from minority backgrounds were much more likely to catch Covid and suffer long term effects. We tried to look at what the Trust could do to support these colleagues. Some of the ethnic communities had more concerns about the vaccine, so the Trust held webinars trying to dispel some of the myths. We have a lot of ongoing experience of engaging with faith leaders, who can support their communities, which helped. Ours is a very ethnically diverse community, southern Asian and eastern European but the biggest translation need was for Romanian. So, a very diverse community with very diverse needs.
We need to make sure of what works for them and that they can access it.

CH: Going back five to ten years the attitude could have been described as “This is the service; you have to engage with it”. I think this has changed over the last 18 months; we recognise that we need to find another way to make it easier to access medicines. There is (rightly) a lot of focus on BAME communities but Artur, what is your experience here?

AP: I have been in the UK since 2005 in professional environments. I'm comfortable having these conversations in English. However, when I go to take my car to the garage or, for example, talk to builders, it is a different vocabulary and I still struggle to communicate what I want. Even with the younger generation, when it comes to health those people have significant barriers as they don't know how to explain what they need, so sometimes they just go to see a doctor when back in Poland. With the pandemic and limited access to travel, telephone consultations are a challenge. Even if your communication in English is good, you may have an accent and it is hard to express what you are saying.

CH: So, we need to think about groups of patients with no English but also those with apparently good spoken English who may struggle with technical terms; the language may not be there for that. So, there is an important message here. Don't assume everything is ok.

SQ: Where we are geographically based in London, it is very affluent but also covers some very deprived areas of East London. Covid exacerbated things for us in terms of visitor restrictions. This meant that patients who rely on relatives to communicate when in hospital couldn't have them there to advocate for them. This made a difference for end-of-life care, when people want particular comfort from someone speaking their language. It is non-verbal communication as well. Because of Covid restrictions the translation services have been heavily relied upon. A lot of people can speak the language, but it is the technical terminology that is much more useful to have in the patient's own language.

CH: So, it is not just about the written instructions, we need to consider pictures and diagrams to help those with language and or learning difficulties. Lama – what's the impact of not being able to understand/read the medicines labels?

LB: I am an interpreter in London, but there are not enough interpreters and this is causing a lot of problems. For example, it has been reported that **12%** of admissions to hospital are due to adverse drug reactions. The patient may have taken an overdose, or not taken the drug, or taken too small a dose, etc. If there is no interpreter and you don't get the label in both languages then there is a real risk of things going wrong.

I help my mother-in-law who has a daughter with a severe disability. I can help sometimes but I can't always be with them. Then they face difficulties because labels are not there and when at home there is confusion as to what they need to take. My mother-in-law is in her late seventies and doesn't retain some of what's been said to her. For example, she thought a suppository was to be taken orally and I had to tell her not orally. We need to have more interpreters and give translators information for medicine labels. Another example is people on lots of medicines, sometimes twenty, and they can't remember which medicine is which. They need organised support, because this is about saving lives. We need to emphasise the importance of more interpreters and having translated labels printed.

What are our professional and regulatory responsibilities around language issues?

CH: The bare minimum should be translating labels. Written Medicine has met with much resistance. We are failing in our responsibility as pharmacists, it's our minimum first step. How do we engage those who don't see the challenges? What are the carrot/stick policy levers to move this forward more quickly?

LM: For the General Pharmaceutical Council, one of the really important levers is the standards for pharmacy professionals. We have two standards that are really relevant; the first is person-centred care, and the second is communicating effectively. We describe standards as outcomes-focused; they're not prescriptive in telling pharmacy professionals what to do and there are different ways to meet the standards. But they do require pharmacy professionals to overcome barriers to communication. Through our consultation on our EDI strategy, we have been running focus groups and hearing from lots of people supporting and representing different patients. It has been really useful hearing about the diverse challenges being faced day-to-day and examples of pharmacy professionals delivering person-centred care. As a regulator, we want to share these examples of good practice. The patients we have spoken to (through our virtual focus groups), have talked about the importance of not making assumptions; treating people as individuals. Standards are the way we want to look at this and an important theme in the equality strategy is to tackle discrimination and make sure pharmacy professionals are tackling health inequalities and providing person-centred care.

CH: Amandeep, can you share with us the role of the Royal Pharmaceutical Society (RPS) and your work around diversity and inclusion?

AD: Our work is initially profession-focused; we are picking up health inequalities separately. One element is how do you address communication barriers and how does this impact upon patients? This conversation is also making me think of theme three - healthcare service delivery - of the Joint National Plan for Inclusive Pharmacy Practice in England, March 2021. There is a risk element to working in community pharmacy when you have no way to communicate effectively with your patients. How do you quality assure and make sure we do it in a safe way? There is a role for us in sharing good practice to make sure people are aware of what to do.

What are primary care networks and trusts doing already to address unmet needs?

CH: The thing I am most proud of about my profession is that pharmacy is very diverse. Succeeding in pharmacy is about how hard you work. But we can only use this feature to our advantage if our actions focus around what we do for our patients. Primary Care Networks have been set up. How has it been for you (HK) with the issues we have discussed?

HK: From a primary care point of view, we have PCNs now and one key role for them is to look at population health management. Who do you have at the heart of the community? What is the unmet need in the community? We have done a lot of work around asylum seekers and refugees, and have had to reach out to them to say there is still access to healthcare – unmet need becomes a challenge. We have one patient who we were able to link to wraparound care. We flagged this up through the primary care framework and were able to link with pharmacy and social prescriber colleagues to support through long term condition management and address how the family support them with this at home. We are mandated through national contracts to do this. We are still encouraging parents to bring in children for vaccinations. I feel I have important insight into some of these patients; I didn't learn English until I went to school so I understand the alien environment and that you don't fit into that space; you feel a bit lost.

CH: Mary – was it as straightforward in your Trust? Were there barriers to getting funding for something like Written Medicine?

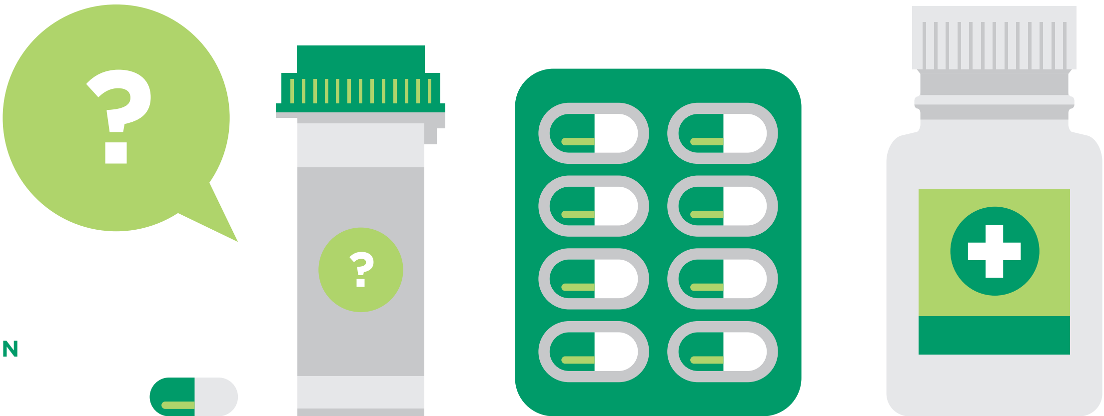
ME: It's so obviously the right thing to do, we didn't have problems convincing the Trust – they were onboard that it is the right thing to do, particularly in the community we serve. We are not just talking about South Asian languages; also European communities and people with learning disabilities. If we're not doing this, we aren't considering our patients. One interesting way we have used this is that we have a number of children with complex needs. They are on multiple medicines at multiple times of the day, and we are discharging these children to their families who haven't necessarily got English as their first language. The complexity of labelling, doses of milligrams/micrograms meant that parents were having to spend a lot of time in the hospital learning how to manage the medicines administration process. We have now started to translate labels into the patient's language (using Written Medicine), and parents are so pleased. They have confidence that they are giving the correct medicines and doses. The paediatric team are fully onboard and pleased. This has been the biggest success for us.

CH: A clear message is that pharmacy need to lead this. There are hidden groups of patients who are not thought about straightaway. Examples include children whose parents don’t speak English, and adults who appear to speak English well but who may not have the technical language to deal with a healthcare setting or complex medication regimes.

SQ: There are competing priorities. The ‘whataboutery’ that arises instead of saying, “This is the right thing to do, let’s get implementing,” is an issue. A main objection/concern is about it being system-wide. Our Integrated Care System (ICS) is in its infancy: how do we have that golden thread; how does it translate to primary care (if coming through secondary care)? A stumbling block is funding. This kind of conversation is really important as everyone can see benefits and barriers and how to move forward. Our local population who would benefit the most from this is Bangladeshi. We are moving forward, but not at the pace I’d like.

CH: That felt like it was important to bring a group together to highlight challenges faced and competing issues. It boils down to “Have we given patients everything they need to take their medicines well?”. We need to support Written Medicine to get this message across. Artur: what are your thoughts on systematically implementing this? Is primary care a route to solve this?

AP: We have seen it in community pharmacy and have been aware of this problem for a while. I remember we put in a lot of effort to recruit pharmacists that speak Urdu. We knew if we have them speaking these languages it will (positively) impact patients who speak different languages. It’s a little task but a big step forward. It gives patients confidence to talk in their own language if necessary. We should also consider self- and minor illness management; patients often come into the pharmacy as their first port of call. Do we have the resources to give them good advice in their own language? Are translated leaflets available? Is there an equivalent in another language?



CH: We have focused a lot on prescribing. Ghalib, what are your thoughts on Artur's comments about minor ailments, etc?

GK: Our solution can be used for any medicine – over the counter, etc. – and you can just put a dispensing label over it. You're right, we have looked at this with various pharmaceutical companies with their own licences but, due to MHRA regulations, they may have specific requirements that may not be used in the UK. It's available but not applicable universally. The translation has to be available for both prescriber and also the person receiving. Sometimes there are minor ailment treatments from A&E. We worked on a project with Imperial College London, where we translated and printed bilingual A&E discharge letters. Using the example of a head wound; how to best treat it at home, telephone numbers, etc – this can be replicated anywhere in the country. People have asked us to translate appointment letters that go out from hospitals. Those letters are already available in different languages but there's a lack of willingness to go one step further and fund them to be available to all trusts - it's just lack of will to do it.

People use Google translate. This is not a reliable source for medication translations.

So why aren't we putting in language solutions already?

CH: We have heard a lot about reality on the ground. Coming back to Ghalib, what would you like to see for people who are aware of the issues but won't deliver on the solution?

GK: One frequent barrier is the integration of IT systems, and secondary care is better than primary care when it comes to open integration networks. Lack of understanding of the commercial opportunities; this is a worldwide problem. In the UK we get information in English – in many countries you don't get this. It also needs to be sustainable. In my experience, this topic comes up every five years, there is some activity but it is not sustained. It needs championing regionally and nationally/centrally by NHS England. It requires willingness.

Pharmacy Stamp

Age
30

D.O.B
22.05.1990

Title, Forename, Surname and Address
Mr Any Patient
Any Road
Any County
AB2 3CD

Number of days' treatment
N.B. Ensure dose is stated

NHS Number: 123 456 789

Endoresements

Amoxicillin 500mg Capsules
500mg three times daily
Supply 15
(No more items on the prescription)

Signature of Prescriber
A Doctor

Date
25.05.2020

For dispenser
No. of Prescns. on form

Dr A Doctor
Any Health Centre
Any Street
Any Town
AB1 2CD
020 0123 4567

Any CCG
123456

FP10SS0000

What can we do?

CH: How do we start to tackle these issues?

FR: Build a consensus. My worry here is that everyone is keen and sees the need but we are preaching to the choir. What we don't have is the people who are not yet convinced. We need to bring those out. I worry that in a busy and complex world there is a group of people not as motivated and who will only do things when told – how do we move to that situation?

CH: There's almost a movement needed to make it unacceptable for people to not engage with this agenda.

SQ: For those people who aren't convinced – how do we convince them from a medicines optimisation viewpoint where thousands or millions of pounds are going to waste due to people not taking medicines properly, with dire consequences? If we get this right, there are knock-on effects.

FR: There will be a group of people who accept the problem – but what evidence do we have that it makes an impact on the problem. Do we go down a beartrap to get evidence, or do we just say it's obvious?

GK: Pre-Covid we were very much looking at the evidence base; patients from ethnic minorities are least likely to complain and so the issue doesn't even come up. There was a patient receiving outpatient pharmacy services from a trust, who died due to language/communication barriers – many of these cases will not show up with NHSE/I. People have to be seen to be doing something around this. There is change now happening but we are decades behind looking at impact. There have always been language and communication barriers in care. In pharmacy we are playing catch up, but an accelerated catch up.

AD: We are finding regular groups of passionate people who take away ideas, but it's always the same people who come back. How do we get everyone to think about this? A new report from King's Fund to say exactly what we are saying? How many more until people recognise it needs to be done? Sometimes one needs to force this to be done contractually – when does this come in?

CH: In relation to contract and regulation - are we there?

LM: Good question, I want to think more about this when working on strategy. We are hearing more from patients and have identified this as an issue, but want to see what we hear through all the engagement.

CH: So, the ball is in our court as pharmacy professionals say “This is what we need to do now.” There has, I think, been a change – it is no longer acceptable to just say “You need to learn English”. Things are slowly changing.

SQ: I agree; people talk about it more but that doesn’t mean the problem has gone away, rather it has been driven underground. We need to increase the evidence base. When we get to people making decisions around funding, etc, it’s usually on a quantitative basis. It is broader than implementing a particular piece of software and more about how we talk about these things. We will help to provide evidence, but how much more is needed before action is taken?

CH: There are some people for whom you can provide a randomised trial in The Lancet and they still won’t engage. Sometimes you need to create the energy.

ME: From my point of view, it needs to be driven by the ICS. We have the opportunity to do that, having it in isolation in an acute trust is one thing but it needs to be spread into the community. Evidence is always good; we have collected good evidence. But it is quite different to work out how to follow patients going through hospital. In general practice it’s easier to follow-up patients and see outcomes, but in an acute trust we may not see the patient again. We need to think about how we do get evidence; I don’t think it will be easy, but we should try.

FR: Having raised the question of evidence - where interpreter services are available, did they have to justify the use of an interpreter and if not, why set up a different standard for medication labels?

CH: The burden of proof upon us is higher than it is for other services and professions – let’s just keep doing it so it becomes unacceptable not to have translated labels. Reduction in readmission data is always helpful.

GK: In secondary care we’ve not had too many problems but in community pharmacy there were concerns about negligence and liability. What if the translation is incorrect? Who is responsible for this?

CH: People's fear of getting it wrong means they do nothing – we could cause all sorts of harm, but their concern about taking a step, and what that means, is a barrier. Laura, would you rather see people doing something than nothing?

LM: There is a myth around errors in any context that the regulator will take action in all circumstances (it's all about context, learning and change); is that a genuine barrier or a myth to dispel? There is flexibility in how pharmacies can act on these issues and we don't mandate the use of any specific solutions. Probably a communications challenge for everyone.

CH: So Ghalib, what are the checks and balances around assurance/governance?

GK: We have a four-step check and balance to the language and development process. We're happy with just one of our steps – finding an Eastern European pharmacist is easy but Punjabi, for example, is difficult. One thing people mention is they want rubber stamps that our processes have been verified by someone – they want to see there has been some thinking behind creating this innovation. Pointing towards available resources, a lot of people are coming up who need resources, but barriers appear around integration, e.g., is this the correct translation, etc.

CH: We have teased out the issues on the ground: the challenge is to now put those things in place! Do you have any other comments or issues around this agenda that you'd like covered? Ideas that we could explore on your behalf?

GK: One thing people mentioned is political willpower. I have attended some of the previous digital pharmacy meetings. The next steps should be how do we influence this? Bilingual labels are mandatory in America, due to the civil rights movement. Over here we have shown the problem, created the solution and are now asking for regulatory change. Covid has exposed health inequalities, and hopefully we can use all scenarios to enhance and improve how we give out information. For example, in banking there has been so much more forward thinking around accessibility - they have braille, have audio links to connect to headsets, credit card arrows showing where to put the card in the ATM slot. In health the fundamental accessibility stuff is missing.

CH: We have focused on language but learning disabilities are important too.

AP: Express the feeling that the PCNs need to be engaged – we are looking at the bigger picture but we know the impact we have in smaller pockets, but some don't recognise it's vital to improve the inequalities. A number of PCNs are in a difficult position as Helen mentioned.

CH: Other clinical directors back up what Helen said – Helen's role is important in this. Agree that PCNs are the beginning of where we should shape this.

FR: Now you have a list of possible ways forward, but peer pressure seems to be one of them. GK mentioned on an international level the UK isn't leading the way on this. It would be interesting to know whether there are whole countries leading on this. How come banking and legal are doing this but healthcare isn't?

CH: Peer pressure can be enormously powerful. Traditionally, in pharmacy and healthcare, we always wait for a rule of legislation – but led by the right person, a social movement can be powerful and so worth pursuing.

GK: Canada being French and English, it is mandatory to provide bilingual labels. Pharmacists in Canada who are bilingual and mention this as part of their expertise are more attractive to employers.

Why is it not happening in Wales? Someone had a patient with dementia and the only means of communication is Welsh as the patient has forgotten other languages. The only reason there are no bilingual labels in Wales is due to the technical nature of the language. They don't have to provide this in Wales.

ME: Wales is an opportunity as most things are replicated in Welsh and English. I didn't realise it wasn't the same in medicine.

CH: If you want to be a good pharmacist you can't learn all languages, but this shouldn't stop you from providing for patients' needs. The minimum you can do is have Written Medicine there. You're not doing your job well if mechanisms in place are not there. Lama, if we did Written Medicine labels as a minimum, would this help?

LB: Challenges are there, people are finding it hard and it's costing lives, so something needs to be done. If it's as simple as generating labels and having more interpreters to help with that, which is available in the NHS, why would you not do this in pharmacy? I hope this talk has shed light on the importance of this and will make a difference.

CH: Thank you to you all for your contribution.

Actions:

Wessex
Academic Health
Science Network

NHS

@WessexAHSN
wessexahsn.org.uk

TheAHSNNetwork